# Implementing Organizational Design Options for State Cancer Control Planning: Developing Model Comprehensive State Plans

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# PREFACE

Beginning in 1995, the Centers for Disease Control and Prevention (CDC ), Division of Cancer Prevention and Control (DCPC), undertook several tasks to enhance its understanding of comprehensive cancer control programs and what putting them into practice might entail. The information presented in this summary is derived from a project ("Implementing Organizational Design Options for State Cancer Planning: Developing Model Comprehensive State Plans") that traced the development of the concept of comprehensive cancer control. The purposes of the project were to (1) determine the essential elements for planning, (2) provide technical assistance and evaluation support during the planning process, and (3) provide guidance for future comprehensive cancer control planning efforts. This project summary discusses technical assistance that was given to states and summarizes the outcomes of the project by presenting information on the activities that occurred in the early years of comprehensive cancer control programs. In addition, this project summary provides a brief overview of the guidance that was developed and provides direction for future comprehensive cancer control initiatives.

The model planning project served as the practical application of the comprehensive cancer control concept, testing the framework and essential elements and developing new models and tools. The Battelle Centers for Public Health Research and Evaluation, contracted by CDC , used an evaluation approach to determine the nature of challenges in six model planning states. This approach used the knowledge of stakeholders (those interested in comprehensive cancer control) in comprehensive cancer control planning. Next, practitioners from among the model planning states and implementation grantees worked with CDC and Battelle to develop a model for comprehensive cancer control planning that included problem statements, objectives, activities, and outcomes. Finally, Battelle tested the accuracy of the model through an analysis of data collected from states.

Because the project generated much information on the strengths and challenges of the comprehensive approach to cancer control planning, this summary serves to highlight the practical application of comprehensive cancer control planning in six model planning states—Arkansas, Illinois, Kansas, Kentucky, Maine and Utah.

# ACKNOWLEDGEMENT

The information presented in this project summary was extracted from a report submitted to CDC by Battelle in June 2001. The report was prepared by Martha L. Hare, R.N., Ph.D.; Joanne Abed, Ph.D.; Shyanika Wijesinha, M.A.,; John Rose, M.A., ; Carlyn Orians, M.A.; Myrna Candreia M.A.; and Mary Odell Butler, Ph.D., of Battelle Centers for Public Health Research and Evaluation, 2101 Wilson Boulevard, Suite 800, Arlington, Virginia 22201. This publication would not have been possible without the contributions of the cancer control programs of Arkansas, Illinois, Kansas, Kentucky, Maine and Utah.

# INTRODUCTION

## 1.0 An Integrated and Coordinated Approach

As defined by the Centers for Disease Control and Prevention (CDC ), Division of Cancer Prevention and Control (DCPC), comprehensive cancer control is "an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation." The definition is built on the recognition that effective cancer prevention and control planning and programming should address a continuum of services ranging from primary prevention and early detection to effective treatment and end-of-life issues such as pain relief. Comprehensive cancer activities control also incorporate many disciplines, including administration, basic and applied research, evaluation, health education, program development, public policy -making, surveillance, clinical services, and health communications. The efforts of a comprehensive cancer control initiative optimally occur in the context of a formal collaboration of stakeholders and partners across multiple disciplines.

A comprehensive cancer control plan is a way to assess and then address the cancer burden within a given state, tribe, or territory. It builds on the achievements and the infrastructure created for existing cancer-related programs -many of which address individual cancer sites (e.g., breast, prostate) or risk factors (e.g., tobacco use, sun exposure). Planning is accomplished through a partnership of stakeholders, which carefully reviews epidemiological data and research evidence (including program evaluation data) and then sets priorities for action in a systematic way. The partners then work together to mobilize support for implementation of the joint priorities that have been established. Finally, the partnership puts in place a system to institutionalize the initiative as a means to coordinate implementation, to monitor progress over time, and to reassess priorities periodically in the light of emerging cancer-related developments.

## 2.0 Identifying Advantages and Challenges

Historically, the cancer-related programs supported by CDC have been primarily categorical in nature, that is built around specific cancer sites and risk factors. However, CDC staff members, state health agency officials, and other stakeholders involved in cancer prevention and control activities increasingly have noted that coordination among these programs is often not ideal, and they have expressed concern about duplication of efforts and missed opportunities for cancer prevention and control at national, state, and community levels. CDC therefore recognized that further significant growth of cancer prevention and control programs within state health agencies and elsewhere would require coordination and integration of activities to maximize resources and achieve desired cancer prevention and control outcomes.

In 1994, CDC began formally exploring a comprehensive approach to cancer prevention and control and began work with numerous stakeholders to develop a

comprehensive cancer control planning and implementation process. Comprehensive cancer control was an extension of CDC 's ongoing work with state-based health agencies, territories, tribal organizations, and organizations serving racial and ethnic minorities; national health organizations; universities and medical centers; private voluntary organizations; professional associations; consumer groups; and the private sector to enhance the number and quality of cancer-related programs available to the U.S. population.

Between the spring of 1995 and the fall of 1998, CDC conducted a series of meetings and conferences to gather stakeholder input on the feasibility of implementing comprehensive cancer control programs at the state level and on potential barriers to and facilitators of the process. The initial reaction of stakeholders to this innovative concept was that it would be challenging to adopt a comprehensive approach to planning and implementing cancer prevention and control activities[3].

Although virtually all stakeholders agreed that a comprehensive approach had clear advantages over the status quo (represented by cancer site- and risk factor-specific categorical programs), all other aspects of the innovation suggested that its diffusion would be a slow and uncertain process. Implementing a comprehensive cancer control program was not compatible with the status quo, which relied upon categorical funding streams.

## UNDERSTANDING COMPREHENSIVE CANCER CONTROL

Beginning in 1995, CDC undertook several tasks to enhance its understanding of the concept of comprehensive cancer control. These included the development and implementation of a definition and the identification of challenges to the process (consensus-building activities); a baseline assessment of existing comprehensive cancer control efforts (information-gathering activities); and case studies of cancer control programs in states (knowledge-generation activities).

**Consensus-building activities:** During 1997, CDC worked with stakeholders from a variety of federal, state, and voluntary agencies to establish a definition of comprehensive cancer control, and to identify a number of challenges that may surface once the concept is applied. The identified challenges included *(1) organizational disruptions in state health agencies; (2) changes in the role of state government leading to increased decentralization of programs; (3) varying levels of organizational development and resources among the states, tribes, and territories that would develop and implement plans; and (4) categorical funding streams.*

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[3] Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman K. Comprehensive cancer control initiative of the Centers for Disease Control and Prevention: an example of participatory innovation diffusion. J Public Health Manag Pract 2000 Mar;6(2):79-92. Also available at http://www.cdc.gov/cancer/ncccp/tools.htm.

**Information-gathering activities:** CDC worked with consultants from Strategic Health Concepts, Inc., and Battelle to conduct a baseline assessment of current cancer control activities and to determine which might be considered comprehensive as of 1997. This work included a review of state cancer plans and a literature review. One result of the literature review was the development of a Framework for Comprehensive Cancer Control, published in 2000 (see Figure 1). The framework described comprehensive planning as a cyclical process comprising four phases: *(1) setting objectives based on data, (2) using existing research to determine a range of strategies for meeting objectives, (3) planning feasible strategies, and (4) implementing strategies that are effective and yield desired outcomes.*[4]

**Knowledge-generation activities:** In late 1997, CDC contracted with Battelle to carry out case studies in six states. Two of these states, Michigan and North Carolina, were experienced with comprehensive cancer control. Four of the states—Arkansas, Illinois, Maine and Utah—were considering the development of comprehensive cancer control plans. A major purpose of the case studies was to discern the "essential elements" for a comprehensive cancer control initiative[5]. These case studies yielded information on both the prerequisites for comprehensive planning and the likely barriers to and facilitators of implementing programs at the state level. The case studies in the four pre-planning states generated baseline data on prior cancer prevention and control programming in those states. Once the case studies were completed and the information from all six states was synthesized, it became apparent that the "essential elements" necessary for comprehensive cancer control planning to proceed were as follows: *(1) Strong leadership from the state health agency with commitment of one or more staff persons, (2) effective public-private partnerships that bring expertise and resources to comprehensive cancer control planning and program implementation, (3) access to valid planning data and sound scientific expertise to support effective planning and evaluation, and (4) funding to support both planning and implementation of comprehensive cancer control programs.*[6]

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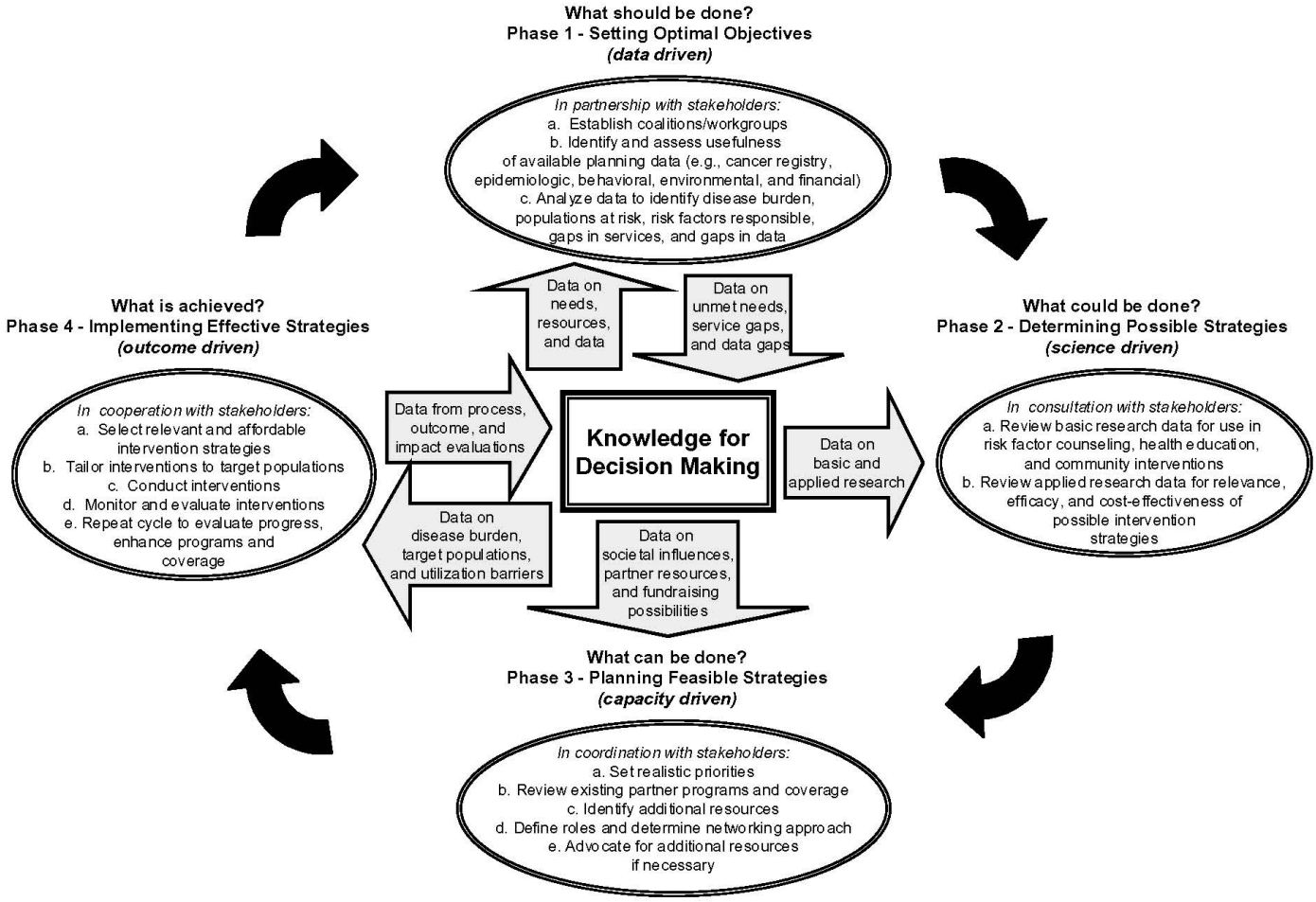
[4] Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman K. Developing a framework for comprehensive cancer prevention and control in the United States: an initiative of the Centers for Disease Control and Prevention. J Public Health Manag Pract 2000 Mar;6(2):67-78. Also available at http://www.cdc.gov/cancer/ncccp/tools.htm.

[5] Butler MO, Abed J, Hare ML, Orians, C, Rose, JM. *Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs: Design Options for State Health Agencies.* Prepared for CDC, Division of Cancer Prevention and Control by Battelle CPHRE. May 1999.

[6] Butler MO, et al. *Op Cit.*. May 1999.

## Figure 2 Framework for Comprehensive Cancer Prevention and Control




## 3.0 The Model Planning Project

In 1998, CDC awarded Battelle contract funds to assist in evaluating technical assistance services to states that were initiating a comprehensive cancer control planning process. During the summer of 1999, Battelle worked with both the six model planning states and the grantees funded for comprehensive cancer control program implementation to develop a model that would be useful for both describing and evaluating comprehensive cancer control activities. Activities related to the six model planning states- Arkansas, Illinois, Kansas, Kentucky, Maine and Utah- evolved into the "model planning project." The selection of these states was based on:

- *Willingness to participate.*
- *Geographic distribution.*
- *Demographics.*
- *Organizational structure.*
- *Public health funding.*
- *Status of cancer registry and use of data for planning.*

Table 1 presents detailed information on the characteristics of these model planning

states at the beginning of the project (1997-1998).

### 3.1 Guidance Document

In early 1999, Battelle worked with CDC to develop a *Draft Guidance Document for Comprehensive Cancer Control Planning*. The purpose of the guidance was to assist planners in designing and conducting a comprehensive state-level cancer planning initiative. In return, the model planning states were expected to provide feedback on the *Draft Guidance Document*[7] so that it could be revised and disseminated more broadly.

**Table 1. Characteristics of Model Planning States (1997-1998)**

| Criteria | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
|---|---|---|---|---|---|---|
| **Breast & Cervical Cancer Program**[1] # of years CDC funding was received | 3 | 3 | 3 | 2 | 4 | 4 |
| **Cancer Registry**[1] Program & funding status | CDC Planning Funding | CDC Enhance-ment Funding | CDC Enhance-ment Funding | CDC Enhance-ment Funding | CDC Enhance-ment Funding | NCI SEER funding |
| **NCI Data-Based Intervention Research Program**[3] | No | Yes | No | Yes | Yes | No |
| **State Health Agency (SHA) Organizational Structure**[4] | Freestanding Independent Agency | Freestanding Independent Agency | Freestanding Independent Agency | Component of Superagency | Component of Superagency | Freestanding Independent Agency |
| **Local Health Departments in the State**[4] (Independent of SHA) | No | Yes | Yes | Yes | Yes | Yes |
| **Substate Health Units operated by SHA**[4] | Yes | No | No | No | No | No |
| **Service providers** | No | Yes | Yes | No | Yes | No |

[7] Hare, ML, Abed, J, Wijesinha, S, Rose, J, Orians, C, Candreia, M, Odell Butler, M. Final Draft*: "Guidance Document for Comprehensive Cancer Control."* Prepared by Battelle in Collaboration with CDC, Division of Cancer Prevention and Control (DCPC), March 2001.

| Criteria | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
|---|---|---|---|---|---|---|
| **operating under contract or grant from SHA**[4] | | | | | | |
| **State funds for cancer control**[1] | Yes | No | No | No | No | No |
| **Total Public Health Expenditures**[4] (in thousands of U.S. dollars) | 112,076 | 460,927 | 102,877 | 206,038 | 29,839 | 69,271 |
| **Medicaid 1115 Waiver**[5] | Yes | Yes | No | Yes | No | No |
| **U.S. Region**[6] | South | Midwest | Midwest | South | Northeast | West |
| **Population Density**[6] # of persons per sq. mile | 46 | 209 | 31 | 94 | 40 | 22 |
| **% Rural Population**[7] | 46 | 15 | 31 | 48 | 55 | 13 |
| **% Urban Population**[7] | 54 | 85 | 69 | 52 | 45 | 87 |
| **% African American Population**[7] | 16 | 15 | 6 | 7 | 0.4 | 0.7 |
| **% American Indian Population**[7] | 0.5 | 0.2 | 0.9 | 0.2 | 0.5 | 1 |
| **% Asian Population**[7] | 0.5 | 2 | 1 | 0.5 | 0.5 | 2 |
| **% Hispanic Population**[7] | 0.9 | 8 | 4 | 0.6 | 0.6 | 5 |
| **% Population ≥ 40 yrs of age**[7] | 41 | 38 | 38 | 39 | 40 | 29 |

Sources of Information:

1. CDC (National Program of Cancer Registries, National Breast and Cervical Cancer Early Detection Program, CDC staff members)
2. Expert Interviews-Interviews with national experts on cancer prevention and control
3. National Cancer Institute
4. Public Health Foundation-Public Health Agencies, 1995
5. Health Care Financing Administration; National Association of State Medicaid Directors; approval for the 1115 waiver allows states to conduct mandatory enrollment of Medicaid recipients in managed care plans.
6. County and City Data Book, 1994
7. U.S. Census, 1990

### 3.2.1 State- Specific Technical Assistance

The model planning project had two major components, one of which was *technical assistance.* The purpose of technical assistance (TA) was to improve progress in comprehensive cancer control planning in each of the six model planning states. While some generic technical assistance was applicable to the project as a whole, most was tailored to the needs of individual states. Within a year of initiating the planning project, it became apparent that certain concerns were common across states, and that information shared with one state could be refined and shared with other states as well.

The kinds of technical assistance offered included *(1) interpretation of the guidance document; (2) monthly conference calls between CDC , each state, and Battelle; (3) all-state conference calls approximately once a quarter; (4) annual meetings; and (5) site visits.* Most technical assistance was provided by teams that included lead state planning staff members, a CDC program consultant, and a Battelle TA liaison. CDC and Battelle representatives either provided technical assistance themselves or worked with other consultants or agencies to obtain the necessary services or information. A major source of technical assistance was peer mentoring in which states provided assistance to one another. This was an outgrowth of either informal requests from one planning state to another via telephone or electronic mail, or formal requests for assistance from planning states to those already receiving grants for implementation of comprehensive cancer control plans.

**Monthly conference calls and TA requests:** While the *Draft Guidance Document* provided written TA to all six model planning states, monthly conference calls formed the underpinning of TA for individual states. These calls were an opportunity for planners in each state to meet by telephone with their CDC program consultant and the Battelle TA liaison to discuss progress and technical assistance needs.

**On-Site Observations and TA:** CDC technical monitor and the Battelle TA liaison visited each model planning state to discuss technical assistance needs and to develop a very brief TA work plan for that state. The kinds of TA requests by states included requests for expert meeting facilitation, assistance with developing a strategy for assessing the economic burden of cancer, and assistance with formatting and editing a state comprehensive cancer control plan. Additionally, CDC and Battelle representatives attended state planning meetings. This visible support helped promote buy-in for the project among stakeholders

### 3.2.2 Peer Mentoring

In the early months of the project, states that were ready to begin planning activities sought opportunities to work with grantees that were already implementing comprehensive cancer control. Later, model planning states mentored each other. The following are some highlights of peer mentoring include:

- Maine held its first partnership meeting in April 1999. Michigan participated through a closed circuit television setup. Experienced staff and external partners

from Michigan provided invaluable information on partnership building.

- Kentucky, a model planning state, was concerned with developing goals and objectives across the continuum of cancer control activities (i.e., primary prevention through end-of-life issues). North Carolina had developed several strategies related to educating professionals and the public on pain management. CDC arranged for pain management specialists in North Carolina to attend one of its monthly conference calls with Kentucky.

- Illinois held its first partnership meeting in October 1998, making it the first of the six states to hold such a meeting. In preparation, staff members developed a survey of partner interests and capabilities. This survey proved so useful that it was passed on to each of the remaining five states, in turn, with each one modifying it slightly or substantially to meet its own needs.

- Using information supplied by the CDC, Battelle, and other states, Maine created a summary matrix that synthesized key decisions about the organization of the planning effort in six states and in the Northwest Portland Area Tribal Board. Maine shared this matrix with each of the model planning states.

- The Director of the Kentucky Cancer Registry attended an internal work group meeting in Arkansas and spoke about ways of sharing data with communities. The presentation led to a commitment within the Arkansas Department of Health to improve its cancer registry. Over time, the visibility of the registry increased throughout the state.

### 3.2.3 All-State Conference Calls

Through a series of conference calls, all of the model planning states were able to obtain timely information about one or more topics pertinent to their comprehensive cancer control initiatives. The conference calls are briefly summarized as follows:

***April 1999-General overview and update.*** Most states were addressing the infrastructure for planning, and concerns about obtaining personnel and other resources were paramount. Two states were moving forward quickly with partnership building and early planning activities and were able to share some of their concerns and successes related to bringing stakeholders together.

***June 1999-Using data for planning.*** This conference call included presentations by two veterans of comprehensive cancer control planning in North Carolina. The director of the cancer registry emphasized that all decisions made during the planning process should be based on findings from data analysis. Data-based prioritization and decision making reduces controversy in both the planning and implementation stage. Additionally, the cancer registry staff should work closely with program planners so they can report and analyze data as needed.

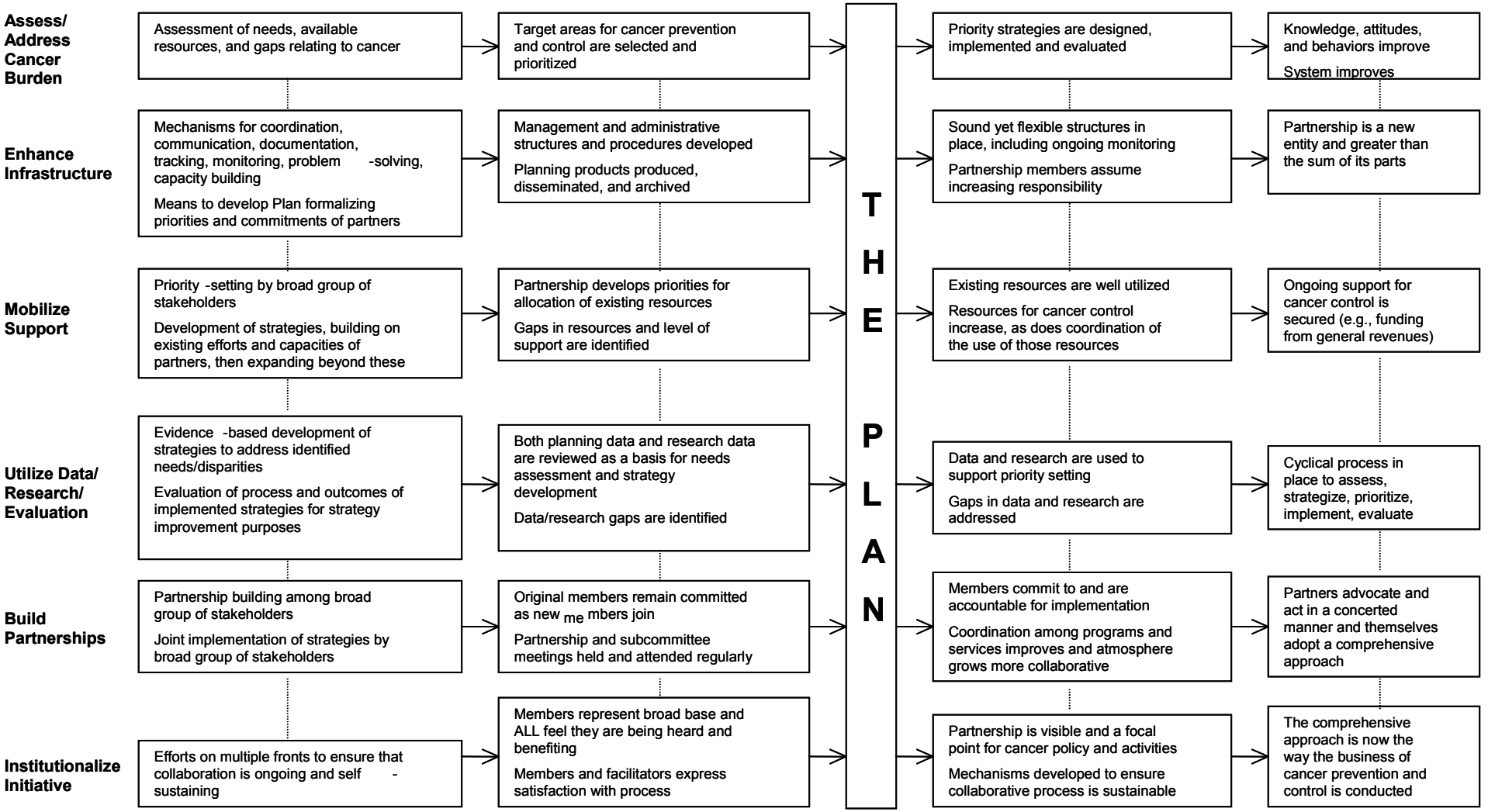
A former staff member for the Care Subcommittee in North Carolina discussed assessing data gaps and finding new data, with emphasis on the importance of using maps when presenting data. Both presenters recommended using visual aids, such as bar graphs, pie charts, and maps, to present and disseminate information to members of the state legislature.

***July 1999-Evaluation.*** In the summer of 1999, CDC and Battelle scheduled a conference call in response to a technical assistance request from the planning states for help in evaluating their comprehensive cancer control planning initiatives. Eventually, responses to the states' questions became the basis for the Conceptual Model of Comprehensive Cancer Control (Figure 2).

Drawing on previous conceptual models, and using practitioner input and feedback from the planning states, CDC and Battelle developed the Conceptual Model of Comprehensive Cancer Control (see Executive Summary). The model was used both as an operational framework for undertaking a comprehensive cancer control initiative and as a framework for evaluating such an initiative. The model begins by positing the reasons for engaging in comprehensive cancer control. It then outlines general activities a state or other organization might undertake to meet each of six objectives, and summarizes the outcomes that can be expected for each objective over time as the comprehensive cancer control initiative evolves. The premise that the conceptual model is founded on is that implementing a comprehensive cancer control plan will require a broad array of partners and more resources than any one agency or organization can provide.

The conceptual model recognizes that it is entirely possible for a small group of committed individuals (e.g., in a state health agency) to *assess* the cancer burden and produce a comprehensive cancer control plan that documents recommended strategies for alleviating the burden. However, that same small group could expect major difficulties when attempting to alleviate the cancer burden (i.e., implement their plan). The conference calls revealed that a plan would be less likely to "sit on a shelf" if partners were involved in planning activities and were not simply called in to implement it. This concept is reflected in the model.

## Figure 2 Conceptual Model of Comprehensive Cancer Control



***December 1999 - Assessment of the TA strategy.*** As expected, by the end of 1999 it was apparent that the model planning states were moving forward at different rates and with some differing needs. A conference call was scheduled that sought to answer the questions, "*Where would you (model planning states) like to be a year from now in your model planning process? And, what TA approaches and resources will you need to get there?"*

Half the states (Illinois, Kentucky, and Maine) expected to complete a comprehensive cancer control plan within the year, while the others (Arkansas, Kansas, Utah) decided that they needed to spend additional time on infrastructure-enhancement and partnership-building activities. All states were interested in the feasibility of estimating state-level costs related to cancer. This would be an extension of work already completed and described in a white paper detailing the challenges associated with the development of such estimates and recommending that several states work together to generate the resources for accomplishing this task[8]. Three states were interested in having a method for assessing the costs associated with planning. Individual needs included *TA on implementing the comprehensive cancer control plan, TA on evaluation, help with developing a community assessment, and assistance with technical writing and formatting the comprehensive cancer control plan.*

***January 2000 - Looking Ahead to Implementing and Sustaining the Plan: Reassessing Partnership Commitment.*** This conference call began with presentations from representatives of North Carolina and Michigan about the transition of their partnership activities from planning to implementation. Next, model planning states shared their own experiences showing that partnerships are dynamic, and addressed evaluation by discussing indicators for reassessing the partnerships. These included some very simple strategies that highlighted the feedback between evaluation approaches and information needed for planning. For example, l*ook at who is attending meetings as well as how many partners are attending. Ask whether partners are still coming to meetings, and ask whether new people are asking to join. Maintain a database to track the growth of the partnership and make follow-up calls, or even personal visits, to inactive members.*

A concern about funding continually surfaced throughout this conference call. This concern seemed to be increasing in intensity as states moved through the planning process. Participants were asked to think of ways to garner support from "nontraditional" sources, but there was a general feeling that some government (federal and state) support would also be needed. CDC decided that additional attention should be paid to this issue, encouraging states to "think outside the box" when it came to sustaining the comprehensive cancer control process.

***March 2000 - Developing Resources and Mobilizing Support for Planning and Implementation.*** Battelle developed a fact sheet listing information on a wide variety of funding resources including Internet sites and an array of directories. The fact sheet was distributed to the model planning states. The purpose of the fact sheet and the discussion

[8] Provenzano, G. "Assisting States in Preparing Estimates of the Costs of Cancer." Prepared by Battelle for the Illinois Department of Health and for CDC, DCPC, October 14, 1999.

during the conference call was to point out the many ways in which funding could be obtained, whether from government agencies, foundations, or other sources.

The reports from the model planning states pointed out that they were indeed actively engaged in seeking support, even if they did not always recognize the true value of what they were accomplishing until after they had some time to reflect on the planning steps. Some examples are:

- *Arkansas was working to promote comprehensive cancer control planning at meetings about the upcoming tobacco settlement.*

- *Both Arkansas and Kentucky obtained conference grants from CDC . These states' cancer conferences were held in late 2000.*

- *Illinois delivered a presentation on comprehensive cancer control at a general session of the Illinois Public Health Association is annual policy conference.*

- *Maine obtained information from each of the implementation grantees on how they developed resources for implementation.*

- *Utah received a positive response to its partnership survey, with 70 responses from the 120 people surveyed. This approach helped publicize comprehensive cancer control activities while yielding data that comprehensive cancer control planners needed for developing the partnership.*

***The March 2000 quarterly conference call.*** This call marked the end of this part of the model planning project. During the summer of 2000, evaluation activities were emphasized through face-to-face site visits in each state. Then, in fall 2000, the final meeting with model planning states was held in Atlanta.

### 3.2.4 Workshops and Meetings

***December 9 - 10, 1998 - CDC Chronic Disease Conference: Model Planning States Orientation Meeting, and Workshop ("A Comprehensive Approach to State-Level Cancer Prevention and Control Planning - Challenges and Lessons Learned").*** This meeting consisted of two parts: an orientation to the model planning project and a comprehensive cancer control workshop. The workshop provided a concise overview of CDC 's vision and of the Framework for Comprehensive Cancer Control.[9] Key lessons learned presented during the meeting were

- *The process is iterative. For example, Michigan spent many months winnowing its priorities to the 10 that were focused enough to be implemented, but inclusive*

[9] Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman K. Developing a framework for comprehensive cancer prevention and control in the United States: an initiative of the Centers for Disease Control and Prevention. J Public Health Manag Pract 2000 Mar;6(2):67-78. Also available at http://www.cdc.gov/cancer/ncccp/tools.htm.

*enough to represent the major concerns of the state's Comprehensive Cancer Control Consortium.*

- *A skilled, experienced and dedicated staff is necessary, but it can be supplemented with specialized consultants and graduate students.*

- *Having a clear vision is necessary for gaining support and recruiting partners. Creating ownership of and commitment to the process among all participants, including finding ways of giving credit to participants is also necessary.*

- *Engaging a broad base of partners, including system change agents is important.*

- *The convener of the comprehensive cancer control partnership, particularly if a state agency, should be neutral, but should also work to give "thoughtful options" to participants, who tend to be busy leaders within their own organizations.*

- *The coordinator and convening agency need to focus on (1) careful preparation and attention to detail, (2) 'thinking outside the box,' (3) flexibility, and (4) simplicity.*

- *Planning must be evidence-based. Relationships with partners must be leveraged to obtain needed data or develop ways to obtain these in the future.*

***September 1999 - Evaluation Pre-conference Session at CDC 's Biannual Cancer Conference.*** The theme of CDC 's biannual conference was comprehensive cancer control, and all model planning states and implementation grantees attended. CDC and Battelle held a pre-conference session to give participants tools for evaluating a comprehensive cancer control initiative.

This conference marked the first steps toward development of the Conceptual Model for Comprehensive Cancer Control. Input from the model planning states and implementation grantees was synthesized, along with elements from a document outlining CDC 's "expectations" for a comprehensive cancer control initiative. Objectives, derived from the synthesis, were framed as strategic objectives, [10] or broad accomplishments meant to achieve a program goal, namely to develop a comprehensive cancer control plan that would be implemented.

States and grantees were divided into breakout groups, one for each objective. Participants then posited components and activities for each objective and completed the pathway with a set of expected short-term, intermediate and long-term outcomes. Several issues surfaced for each objective. These issues were *(1) the need for resources and funding; (2) the need for good, accessible data; (3) a concern about competition and/or fragmentation of services; (4) partnership building and maintenance; (5) priority setting;*

[10] Butler, MO, Abed, J. "Development of a planning and evaluation framework for the Program Services Branch, Division of Cancer Prevention and Control, Centers for Disease Control and Prevention." Report prepared by Battelle CPHRE for CDC, Contract No. 200-97-0088, Task 6. July, 2000

*(6) evaluation; (7) conducting various kinds of assessments (e.g., baseline, needs, resource, and partner); (8) garnering legislative support; (9) institutionalizing the initiative; and (10) developing health outcomes.* These concerns were eventually reflected in the columns and rows of the conceptual model (see Figure 2).

***October 25-26, 2000 – Reverse Site Visit and Evaluation Workshop.*** The final face-to-face meeting consisted of two parts, a reverse site visit and an evaluation workshop. The reverse site visit afforded CDC and Battelle representatives an opportunity to present preliminary findings from the evaluation site visits that had been completed in each of the model planning states. It also afforded each of the states an opportunity to present their accomplishments. The state accomplishments included the following:

- *Illinois developed an infrastructure for comprehensive cancer control planning and implementation despite beginning the process in an environment of organizational flux. Having a full-time professional coordinator for the effort was key to this success.*

- *Arkansas mobilized support through collaboration with the Hometown Health Improvement Project and through its Cancer Summit. The collaborations resulted in buy-in from top management and pledges of support from some 90 participants in planning activities..*

- *Kentucky prepared a presentation on using maps to disseminate data and information throughout the state.*

- *Utah successfully used a survey to assess partner interests and capabilities and to plan for its initial partnership meetings.*

- *Kansas developed a training workshop for staff members on using Specific, Measurable, Attainable, Reasonable, and Time-phased (SMART) objectives when addressing the cancer burden.*

- *Maine started early to institutionalize the initiative through developing capacity among a broad array of partners.*

## 4.0 Model Planning Project Evaluation Approach

The specific activities undertaken as part of the evaluation, which was developed through the Model Planning Project, were formalized in a May 2000 *Site Visit Protocol*.[11] The major activities of the evaluation were *(1) development of the Conceptual Model of Comprehensive Cancer Control, (2) evaluation site visits, and (3) completion of a State*

[11] Battelle. *Site Visit Protocol for Implementing Organizational Design Options for State Cancer Planning: Developing Model Comprehensive State Cancer Plans.* May 1, 2000.

*Activities Tool (see Appendix 1)*. This approach allowed for a detailed descriptive evaluation of planning and the formulation of guidance for future process and outcome studies, as presented in the *2001 Guidance Document*.

### 4.1 Activities

In mid-2000, as part of the evaluation for this project, Battelle used minutes from monthly conference calls and other sources (e.g., notes from on-site meeting observations, examples of documents developed by the model planning state itself) to develop a matrix that depicted the activities undertaken by each state. The matrix shell came from a table of recommended activities in a 1999 version of the draft guidance document. The State Activities Tool, which tracked expected versus actual activities to establish comprehensive cancer control plans, was completed for each state in consultation with each state and its CDC program consultant prior to visiting the state. The results were then shared with the state at the site visit. Analysis of the tool led to the development of the Building Blocks Model of Comprehensive Cancer Control Planning. (See Appendix 2).

Then, working with CDC and Battelle, each state compared its own progress to what had been suggested in the guidance document. Staff members pointed out areas where they had chosen to deviate from suggested activities and the rationale for doing so, as well as activities they had decided to pursue instead of, or in addition to, those in the guidance. The approach to this evaluation utilized the knowledge of states in comprehensive cancer control planning to *(1) determine the nature of evaluation challenges in the model planning states; (2) develop a model of comprehensive cancer control that included problem statements, objectives, activities and outcomes; and (3) test the model through an analysis of data collected from states.*

Between May and October 2000, Battelle staff members and a CDC program consultant conducted a series of meetings and interviews in each state. Participants included the comprehensive cancer control planning coordinator, the chronic disease prevention program director, core planning team members, expanded team or internal work group members, and active partnership members. Each site visit included a review of the State Activities Tool and discussion of any remaining TA concerns with planning staff.

The interview questions were derived from a set of evaluation questions meant to meet the evaluation objective, "Describe the planning process in each of the six individual states." The evaluation questions are presented in Table 2.

**Table 2. Evaluation Questions for Site Visits**

| |
|---|
| **1. *Planning process and structures*** |
| • What are the components of comprehensive cancer control planning in each state? |

- What are the steps and activities of the planning process in each state?
- Which tools, systems, and structures did each state identify, create, or use to facilitate the planning process?
- What processes or structures emerged as partners moved toward completing a plan that proved critical to the comprehensive cancer control effort (e.g., improved relationships among organizations)?

**2. *Decision-making***

- What were the key decisions made in each state during each stage?
- Who was involved in the decision-making process?

**3. *Recommendations***

- What recommendations did respondents have about the comprehensive cancer control process in their own states?

The interviews were conducted through informal conversations either in small groups or with individual respondents. Two Battelle staff members and a CDC program consultant conducted each interview. Interview topics were key to the evaluation questions and discussion guides were generated for the various categories of respondents, including (1) program staff, (2) chronic disease leadership, (3) core team members, (4) expanded team members, (5) partners, and (6) others with knowledge relevant to the project. Responses were sorted by evaluation question using text analysis software. Battelle summarized the results and gave them to each state for comment.

## 4.2 Summary of Findings Across States

Responses to questions during the evaluation site visits demonstrated that cancer control practitioners and stakeholders were enthusiastic about the comprehensive approach to cancer control (see Appendix 3). Respondents had concerns about implementing the plan and institutionalizing the comprehensive program, but most believed that efforts made during the planning process would lead to these outcomes. Overall, model planning states could point to significant accomplishments despite the fact that they had very little funding, and some began the process later than they had originally anticipated. Reasons for delays included the need to wait for state approval of new staff positions or major reorganization in the health department. In states that began late, once the process began in earnest, they moved deliberately and benefited from the experience of the other model planning states.

The only area in which there was real divergence of opinion and experience was the role of the state health agency. In some states, respondents believed that as the public health leader, the health department could and should play a strong leadership role in comprehensive cancer control planning. Others thought that the state health agency should staff the project but allow others to lead it in one state; the health department's

role was limited to two areas overseeing the contract for planning and advice and consent. These views seemed to be based more on the history of the relationship between governmental and non-governmental agencies than on any single discernible feature (e.g., budget, current health department director). Regardless of the nature of the coordinating agency role in developing and implementing the plan, having a dedicated staff person responsible for the project was considered essential.

Evaluation results pointed to the importance of building and maintaining a diverse partnership, as well as to the need to leverage support from partners for implementation of the plan. Respondents appreciated good relationships with data staff, but were concerned about the lack of data in a number of areas, such as quality of life, or obtaining data on risk factors from persons not represented in the Behavioral Risk Factor Surveillance System (BRFSS). In general, respondents agreed that evidence-based planning is best, but planners should keep in mind that new evidence may be found in the future and that a mechanism may be needed to incorporate new data and new approaches at that time.

Clearly, the need for dedicated staff support was a major finding, but progress was made in the following areas:

- **Assess and/or Address Cancer Burden:** All states met the outcome of selecting priority areas for cancer prevention and control activities. Assessment was generally accomplished by work groups that developed objectives and strategies. Kentucky, for example, met this outcome through the work of its core team, with input from selected stakeholders, and by reviewing categorical plans and Healthy People goals and objectives for the state.

- **Enhance Infrastructure:** A major finding was that without attention to infrastructure at the coordinating agency, a comprehensive cancer control initiative could not be successfully initiated. Eventually, the first planning outcome of the matrix, development of management and administrative structures and procedures, occurred in all six states through the efforts of planning coordinators who were supported by core teams of coordinating agency staff and expanded teams of dedicated staff members and key partners. Each state was able to develop systems for producing, disseminating, and archiving planning products such as meeting minutes, activity logs, and drafts of goals, objectives, and strategies. Maine, for example, expanded its coordinating committee composed of state staff members and leaders to initiate the implementation of its newly completed plan. The state incorporated a plan for program institutionalization into the overall state comprehensive cancer control plan and developed an ad hoc committee to deal with this issue.

- **Mobilize Support:** Support includes financial resources, political will, and community buy-in. Initially, the planning partnership had to develop priorities for allocation of existing resources. Three states (Kansas, Maine, and Illinois) had iterative processes for prioritizing objectives or strategies based on the availability of resources or sponsors to implement them, and other states were preparing to do the same. All states identified gaps in resources and levels of support as part of the planning process. Most were able to develop ways of addressing those gaps, although the outcome of many of these efforts was not clear at the end of the study period. There was evidence of modest progress toward implementation and program outcomes for mobilizing support, particularly investigating ways of obtaining ongoing support for cancer control activities. Some states looked toward varied sources of funding (e.g. grants, legislation). For example, in Illinois, a bill was introduced to allocate $500,000 for comprehensive cancer control. Although the bill did not pass, this was still considered an important first step toward legislative recognition and perhaps future financial support.

- **Utilize Data/Research/Evaluation:** All states found ways of meeting the planning outcome of reviewing both planning data and research data as a basis for needs assessment and strategy development. However, the ease of accomplishing this varied depending on the adequacy and accessibility of the data resources. In states with well-developed data resources, it was simply a matter of cooperating with data staff to access those data. In states where data resources were less well developed, the comprehensive cancer control planning process itself focused attention on the state's data resources and led to actions to promote development and improvement of data. Kinds of data used to support the comprehensive cancer control planning process were (1) incidence and mortality data; (2) Behavioral Risk Factor Surveillance System (BRFSS) data; (3) other kinds of data from state agencies (e.g., hospital discharge data, Medicaid/Medicare data); (4) data from partner organizations; and (5) data from research literature on effective interventions. Staff members who helped incorporate data into the planning process included state epidemiologists, cancer registry staff, and others in charge of state data sources. Kansas, for example, developed a unique way of employing data experts through its designated "backgrounders" (data experts in a particular topic area). A second expected planning outcome was the identification of research gaps. This occurred in all six model planning states.

- **Build Partnerships**. The first expected outcome for partnership building was that original members would remain committed as new members joined the partnership. Partnership-building activities in the model planning states included (1) identifying potential partners; (2)

assessing interest and commitment of stakeholders; and (3) establishing structure, vision, and broad goals for the partnership. Model planning states sought to include new members while maintaining a solid group of original partners committed to both planning and implementation. The model planning states tended to have open membership structures that did not limit membership, even though accommodating new members and bringing them "up to speed" created considerable work for the planning coordinator. Kentucky did not have an active planning partnership, but sought stakeholder input for plan development and partner support for implementation. Most states planned through work groups or subcommittees. States expected that meetings of both the partnership as a whole and of the subcommittees or work groups would be held and attended regularly. This was true for four of the states where the work groups were established. There was evidence of moving toward meeting the implementation outcome in that members began to signify that they were committed to and willing to be accountable for implementation. For example, Maine's partner organizations had to sign up to sponsor an objective or goal for it to be included in the plan. In Illinois, sponsorship of strategies occurred after completion of an action plan through the action reports developed by their partners. In Arkansas, partners were asked to signal their commitment to plan implementation at the very first partnership meeting. Each of the six states showed evidence that coordination among programs and services was improving and that the atmosphere was growing more collaborative.

- **Institutionalize Initiative**. In developing the conceptual model for comprehensive cancer control program, states thought that the quality of the partnership would be key a factor for institutionalizing the initiative. Commitment, based on a broad member base, would eventually lead to a visible partnership that served as a focal point for cancer policy and activities in the state, territory, tribe, or other organization. It is apparent that states are conducting activities that may lead to such an outcome. For example, to ensure a representative and inclusive partnership, some states, such as Utah, took deliberate steps to assess gaps and recruit new members. Model planning states also developed ways of ensuring member satisfaction with the process. These included paying attention to the quality of both the partnership and work group meetings and maintaining contact with members between meetings. Maine formally considered program institutionalization early in its process and designed a structure for ensuring an ongoing comprehensive cancer control initiative this structure was presented to partners as part of the state's plan.

Clearly, the need for dedicated staff support was a major finding, but progress could be made with modest resources. Chapter 5 first revisits the issue of organizational structure and then discusses the application of the evaluation findings to future guidance for comprehensive cancer control.

## 5.0 Organizational design options for comprehensive cancer control planning?

Early in the model planning project, developers thought that specific organizational options could be designed for particular types of planning environments (e.g., highly centralized with leadership in state health agency, diffuse planning partnership but with leadership in state health agency, leadership outside the state health agency). The evaluation findings showed that the process is too complex for such a thorough synthesis of the evaluation findings. Planners realized that the Conceptual Model of Comprehensive Cancer Control (see Figure 2) provides a good representation of the comprehensive cancer control process.

The analysis of the project findings confirmed that there are broad stages of comprehensive cancer control planning, as presented in the 1999 version of the *Draft Guidance Document*. While the underpinnings of the conceptual model for both planning and implementation were strong, the actual processes in planning states could be conducted somewhat differently. Therefore, planners designed a model that focused on specific activities within each building block necessary for developing a planning process and continuing through the completion of the comprehensive cancer control plan. They determined that the activities suggested at that time should be streamlined and arrayed in a format similar to that of the conceptual model but should focus solely on planning.

The Building Blocks of Comprehensive Cancer Control (see Appendix 2) was developed and formed the basis for the G*uidance for Comprehensive Cancer Control Planning (2001).* It should be emphasized that the building blocks model does not supersede the conceptual model. Rather, the conceptual model speaks to the entire comprehensive cancer control process, while the building blocks model was developed specifically for states and other organizations that are undertaking a planning initiative.

The tailoring of the building blocks model occurred in large part through analysis findings from both of the State Activities Tool evaluation and the evaluation site visits. These results were compared with the conceptual model. Therefore, a model that focused on the activities within the building blocks necessary for developing a planning process through the end-point of completing the comprehensive cancer control plan was developed.

Developers of the revised guidance realized that the conceptual model was too abstract to form the basis of guidelines for comprehensive cancer control planners. During evaluation site visits, state-based practitioners said that concrete assistance with day-to-day problems or challenges was a useful form of technical assistance. In addition, the findings from the State Activities Tools evaluation revealed that state staff members often modified the original guidance to meet their needs. Therefore, the revised guidance would have to be highly focused and practical.

Drawn from extensive observational data collected from the six comprehensive cancer control model planning states, the building block model has the following features that link it to, yet distinguish it from, the essential elements and the previous two models. The building block model

- *Demonstrates that the implicit "themes" in the framework model and the "essential elements" identified in the initial comprehensive cancer control case studies are actually building blocks that are necessary if a state, territory, or tribe is to assess and address its cancer burden in a comprehensive manner.*

- *"Zooms in" on the activities column of the conceptual model, providing further detail on specific activities that can be undertaken during comprehensive cancer control planning in relation to each building block. By contrast the conceptual model is outcome-oriented.*

- *Separates the objective for data, research, and evaluation into two distinct building blocks (Utilize Data/Research and Conduct Evaluation). The need for this distinction was recognized as a result of an analysis of the technical assistance needs of the model planning states.*

- *Ends with a list of expected planning outcomes by building block and with achievement of the planning goal, namely, production and dissemination of the comprehensive cancer control plan.*

- *Does not include a row for program institutionalization since this is not expected during the planning phase.*

CDC and Battelle sought to assess the utility of the original *Draft Guidance Document.* It was possible to assess which of the suggested activities were realistic, which activities would have been useful but were not widely pursued (mainly evaluation processes), and which activities were not useful for comprehensive cancer control planning. Through comparative analysis of the State Activities Tool, a better sense of the timing of activities was developed. In response to a need identified by states, CDC and Battelle, one area in which activities were suggested beyond those observed was evaluation. This area was addressed intensively during the last year of the project, and the

new *Guidance Document* reflected both the conceptual approach to comprehensive cancer control and real world experience. The time specified for each stage differs markedly.

The State Activities Tool also yielded a time line of activities for each state. These time lines reflected the need for the sequence of activities to follow a general trend, with infrastructure-building activities occurring throughout the process. They specified that activities designed to mobilize support should occur early in the process and then again later, that data collection activities should start fairly soon after the core teams are developed, and that partnerships should then be built in most states. The summary time line as presented in Figure 3 uses 24 months as the standard planning period.

## Figure 3. Summary Timeline of Comprehensive Cancer Control (CCC) Planning

| | 1 - 3 Months | 4 - 6 Months | 7 - 9 Months | 10 - 12 Months | 13 - 15 Months | 16 - 18 Months | 19 - 21 Months | 22 - 24 Months |
|---|---|---|---|---|---|---|---|---|
| **Enhance Infrastructure** | Assess infrastructure needs and capacity. Gain buy-in from leadership of coordinating agency .identify/hire dedicated coordinator/staff. Create core planning team. | Involve other cancer-related coordinating agency staff. Develop work plan to guide the planning process. | Coordinate and monitor the CCC planning process. | | | | | |
| **Mobilize Support** | Assess current level of support. Secure funds and in-kind resources for planning. | | Build support among the public and private sectors. | | | Publicize efforts of the partnership. | Develop approaches for funding plan strategies. Reassess partnership representation & coverage for implementation. | |
| **Utilize Data/Research** | Build linkages to registry and other data agencies and sources. | Identify available data/research. | | Review data and research as the basis for plan objectives and strategies. Assess data gaps. | Collect new data if feasible and/or incorporate data collection/ research into Plan. | Identify or collect baseline data against which to measure outcomes. | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Build Partnerships** | | Identify potential partners. | Contact and invite potential partners.<br>Assess partner interest and capacity.<br>Prepare for first partnership meeting. | Agree on goals, vision and decision-making process with partners.<br>Establish partnership leadership.<br>Create work groups.<br>Assess partner satisfaction. | Develop ways for new members to join and non-members to provide input. | | | |
| | 1 - 3 Months | 4 - 6 Months | 7 - 9 Months | 10 - 12 Months | 13 - 15 Months | 16 - 18 Months | 19 - 21 Months | 22 - 24 Months |
| **Asses/Address Cancer Burden** | | | | Organize partnership around areas of interest. | Determine critical areas of burden and high-risk populations<br>Assess gaps in strategies already in place. | Create measurable goals and objectives for Plan. | Identify possible intervention strategies.<br>Prioritize objectives and strategies. | Identify implementing organizations for Plan strategies. |
| **Conduct Evaluation** | | Identify resources and staff for evaluation.<br>Define planning evaluation questions.<br>Document the planning process. | | Identify emerging challenges, solutions and outcomes of the planning process. | Provide TA/training on evaluation to partners. | | Create evaluation plan for implementation. | |

## 6.0 Summary and Recommendations

Findings from the Implementing Organizational Design Options for State Cancer Planning: Developing Model Comprehensive State Plans project, as well as reflection upon the experiences of providing technical assistance, found that states needed specific guidance during comprehensive cancer control planning stages (see Table 3). The recommendations presented below are grouped according to the six conceptual areas, plus one additional topic - conducting evaluation. Evaluation was included as a seventh topic because an analysis of technical assistance provided during the course of the model planning project demonstrated that states need guidance in incorporating evaluation early in the planning process for a comprehensive cancer control initiative.

**Table 3. Recommendations for Comprehensive Cancer Control Planning**

| Topic | Recommendations |
|---|---|
| **Assess/Address Cancer Burden** | *Develop a structure for partner input.* The major structure for including partners in the work of assessing and addressing cancer burden was a work group or subcommittee that was developed around an issue or category to be addressed by the comprehensive cancer control plan.<br><br>*Focus work groups on categories that are selected by the partnership.* There is no one way of defining the nature of work groups. Some states prefer work groups that are focused on cancer sites or risk factors (e.g., breast cancer, tobacco control), while others favor cross-cutting issues (e.g., access to care). Partners should have buy-in to the structure of the work groups, and the structure may be assessed and modified at critical junctures such as the transition from planning to implementation.<br><br>*Develop a common language.* Often people from different backgrounds define terms such as goals, objectives, indicators, outcomes, strategies, and priorities differently. Be sure that everyone is using the same terminology when writing sections of the Plan. Train facilitators to use worksheets that are easily reviewed by staff or a core group of partners.<br><br>Have a clear strategy for setting priorities. Priority setting does not occur once, but at multiple times throughout the process. This includes setting priorities for what to include in the Plan, and what to implement once it is developed. Having clear procedures for developing priorities at each stage of the process is important, as is ensuring that all members understand what procedures and criteria will be used. It is important to recognize that each proposed goal, objective and strategy is important to at least one member, and so a decision-making process that is both clear and inclusive goes a long way toward ensuring buy-in for those goals, objectives and strategies that are eventually selected. |
| **Enhance Infrastructure** | *Foster progress by having dedicated staff. A* comprehensive cancer control effort requires the time and attention of a dedicated staff, ideally with a full-time coordinator. However, if this is not possible a part-time staff can be effective provided it is given a great deal of support from supervisors and peers.<br><br>*Build a comprehensive cancer control planning team.* Having a core team made up of staff members active in cancer-related issues (e.g., epidemiologist, etc.) is crucial for supporting the comprehensive cancer control coordinator.<br><br>*Supplement the core team before developing a full partnership.* An expanded team or internal work group can be seen as a first-level partnership - that is, partners from within the coordinating agency and perhaps a few key external agencies (e.g., American Cancer Society). The expanded team reviews products of the core team, provides further input into decision-making, and may take on other tasks as well.<br><br>*Consider all possible "homes" for comprehensive cancer control planning.* Although the above recommendations cite state health agency staff members as examples of whom to include in the core team and, to a large degree, the expanded team, the staffing pattern can be adapted to the structures of a variety of agencies. Among the model planning states, Kentucky housed its program in a university-affiliated cancer program. Other possibilities exist as well. |

| Topic | Recommendations |
|---|---|
| **Mobilize support** | *Make strategic decisions about partners.* Support is needed from a broad sector of the population, including representatives of organizations likely to implement Plan strategies, legislators who can provide political support, representatives of target populations, and representatives of organizations that may be able to fund strategies.<br><br>*"Think outside the box."* When considering funding sources, explore opportunities beyond government agencies. Pharmaceutical companies, health insurance organizations, foundations, and businesses that are visible in the community are just some of the entities that may support components of the comprehensive cancer control plan.<br><br>*Be alert to opportunities for supplementing the staff.* Local universities can contribute staffing support or consultation, particularly in program evaluation. Two model planning states received staff members from CDC 's Public Health Prevention Specialist Program who will help lead the planning project into implementation.<br><br>*Go public.* Model planning states used approaches like displaying posters, speaking at state-wide events, and applying for CDC conference grant funds to host large-scale comprehensive cancer control conferences. |
| **Utilize Data and Research** | *Invite Cancer Registry staff and other data and surveillance professionals to participate in planning on several levels.* Invite registry staff and other critical professionals into the process early. Opportunities for participation include acting as core team members, expanded team members, partners, work group members, work group facilitators, or expert presenters or reviewers. Consider whether a data and surveillance work group or subcommittee should be formed, or strategically place individuals who are knowledgeable about data use in as many of the work groups as possible.<br><br>*Use the knowledge of clinical and academic experts.* Clinicians and academics, as well as graduate students, can contribute to an understanding of research reports and other relevant scientific literature necessary for deciding on objectives and strategies. Those who are too busy to join the partnership may function as "expert consultants."<br><br>*Work with data experts to make presentations to other partners "user-friendly."* Presentations to partners should be meaningful to members with scientific backgrounds, but should also break down key concepts and avoid jargon for those whose backgrounds are less oriented to the data sources used in comprehensive cancer control planning.<br><br>*Ensure that key decisions are based on sound data or research reports.* Although comprehensive cancer control planning is an evidence-based process, it may not be feasible to obtain all of the data that are desirable for planning. Therefore, additional data collection or analysis activities may be incorporated into the Plan itself. |
| **Build Partnerships** | *Lay the groundwork before developing the partnership.* A strong foundation can inspire confidence that the comprehensive cancer control planning process will accomplish its goals. Therefore, time spent on enhancing infrastructure, working with the core team and expanded team to seek out data sources and resources, and creating a vision is worthwhile. This will allow everyone to work together in a cohesive manner when external partners are brought on board.<br><br>*Strategize about whom to include in the partnership*. Including partners with very different backgrounds can be challenging, but it also can be rewarding. The greater the diversity in the partnership, the more inclusive it will be and the likelihood of incorporating varied viewpoints will increase. However, there is a trade-off in lower efficiency when the partnership is very broad.<br><br>*Consider ways of involving people who may not have time to participate in all activities.* For example, medical academics with very busy schedules may only be able to serve as advisors or reviewers of products. Clinicians or service providers who work with patients or community agencies may not be able to leave their place of employment, but can join work groups through conference calls.<br><br>*Pay attention to maintaining the partnership.* This can include simple strategies like telephoning partners who miss meetings, or more time-consuming strategies like working to bring in new individuals and organizations over time. Be especially cognizant of groups that may not be represented, or that start to participate but then drop off, and find ways to include them. |

| Topic | Recommendations |
|---|---|
| | *Stay focused on the reason for planning.* Comprehensive cancer control is more than the product, but working toward a product - the comprehensive cancer control plan - is a necessary condition for success. Developing interim products (e.g., meeting minutes, work group reports) and a clear timeline also helps maintain focus. |
| **Institutionalize Initiative** | *Consider the extent to which the partnership will have control over the outcome of planning and communicate this decision to partners.* In general, staff members in model planning states believed that the Plan should be the result of a group process, and that the staff should not dictate what it would look like. Staff should guide the process, but often need to step back and let partners make key decisions about what should be included. The understanding that decision-making will be ceded to the partnership must be communicated early to partners if the Plan is to be a group product and the initiative is to be institutionalized.<br><br>*Develop leadership within the partnership.* Maine, the state that showed the greatest evidence of program institutionalization, encouraged partners to take on leadership roles in work groups and in the partnership as a whole. Partners and staff members also included a plan for program institutionalization within the state's comprehensive cancer control plan. |
| **Conduct Evaluation** | *Develop a vision for planning.* Comprehensive cancer control can become very complex. Therefore, early in the process, the core team should develop a planning road map that lays out a vision of where the state (or other organization) is beginning, its destination, and a limited number of guideposts or benchmarks along the way. Later, partners may revise the road map, and those working on an evaluation plan may add further benchmarks or guideposts to indicate whether the destination is being reached.<br><br>*Create methods for documenting planning activities.* Simple processes and tools for documenting the ongoing activities associated with planning can be valuable. Examples include maintaining minutes of all meetings, making a chronological log of activities conducted, and keeping work sheets used when work groups meet to develop goals and objectives. These items can be reviewed to allow the staff to troubleshoot problems, to assess gaps in partner membership and planning activities, and to prepare for implementation and outcome evaluations.<br><br>*Use local resources. Tap into e*valuation expertise through partners and local universities. Several model planning states and implementation grantees took advantage of the services of graduate students to assist in setting up systems for evaluation and to conduct small-scale assessments of partner participation. Beyond this, consider budgeting for a local evaluation firm or university-based researcher to develop a full-scale evaluation plan, which is critical to demonstrating outcomes once the Plan is implemented.<br><br>*Think about evaluation early and broadly.* Targeting the evaluation requires the formulation of an evaluation strategy before the Plan is implemented. This is why early "visioning" exercises are important, as are methods for documenting the planning process. These activities help the staff and partnership leaders to know if the process is running smoothly and if intermediate outcomes (e.g., development of goals and objectives) are being met. Later, as the contents of the Plan become clear, specific programmatic and health outcome studies linked to individual strategies can be proposed. |

## 7.0 Concluding Thoughts

At this time, comprehensive cancer control is still a fairly new initiative, coming to the fore only in the mid-1990s. The recommendations presented in this chapter were derived from work with CDC and with six model planning states. They also are derived from the knowledge obtained in earlier projects designed to develop a baseline knowledge about comprehensive cancer control. Such projects include a literature review and case studies of states engaging in comprehensive cancer control efforts or contemplating such an approach.

The final synthesis report documented the manner in which the underlying concepts of comprehensive cancer control were developed, applied, and evaluated. As interest in this approach grows in the coming years, it is likely that practitioners and stakeholders will have much new knowledge to add to the field. Therefore,

comprehensive cancer control programs continue to be an evolving process that will yield new lessons well into the future.

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**Appendix 1**

# State Activities Tool

## The Stages and Steps of Comprehensive Cancer Control (CCC) Planning

| Stage and Step of Planning | Building Block Activities |
|---|---|
| **Stage I – Lay the Groundwork for Planning** | |
| *Step 1* – Develop capacity of the coordinating agency to conduct planning. | Assess infrastructure needs and capacity (*Enhance Infrastructure* [EI]).<br>Gain buy-in from leadership of coordinating agency (EI).<br>Identify/hire dedicated coordinator/staff (EI).<br>Create core planning team (EI).<br>Assess current level of support (*Mobilize Support* [MS]).<br>Secure funds and in-kind resources for planning (MS).<br>Build linkages to registry and other data agencies and sources (*Utilize Data and Research* [DR]). |
| *Step 2* – Initiate comprehensive cancer control planning process. | Involve cancer-related coordinating agency staff (EI).<br>Develop work plan to guide the planning process (EI).<br>Identify available data/research (DR).<br>Coordinate and monitor the comprehensive cancer control planning process (EI). |
| *Step 3* – Build the partnership. | Identify, contact, and invite potential partners (*Build Partnerships* [ BP]).<br>Assess partner interest and capacity (BP).<br>Prepare for first partnership meeting (BP).<br>Build support among the public and private sectors (MS).<br>Publicize efforts of the partnership (MS).<br>Agree on goals, vision, and decision-making process with partners (BP).<br>Establish partnership leadership (BP).<br>Create work groups (BP).<br>Assess partner satisfaction (BP).<br>Develop ways for new members to join and nonmembers to provide input (BP). |
| *Step 4* – Develop and carry out an evaluation approach. | Identify funding and personnel resources for evaluation (*Conduct Evaluation* [CE]).<br>Define planning evaluation questions (CE).<br>Document the planning process (CE). |
| **Stage II – Develop the CCC Plan Components** | |
| *Step 1* – Determine goals and objectives. | Organize partnership around areas of interest (*Assess and Address Cancer Burden* [AA]).<br>Review data and research findings as the basis for plan objectives and strategies (DR).<br>Assess data gaps (DR).<br>Identify emerging challenges, solutions, and outcomes of the planning process (CE).<br>Determine critical areas of cancer burden and high-risk populations (AA).<br>Assess gaps in strategies already in place (AA). |
| *Step 2* – Prioritize objectives and create strategies to meet them. | Collect needed data if feasible and/or incorporate these activities into the Plan (DR).<br>Provide TA/training on evaluation to partners (CE).<br>Create measurable goals and objectives for Plan (AA).<br>Identify or collect baseline data against which to measure outcomes (DR).<br>Identify possible intervention strategies (AA).<br>Prioritize goals, objectives, and strategies (AA). |
| *Step 3* – Ensure that strategies are feasible. | Develop approaches for funding plan strategies (MS).<br>Reassess partnership representation and coverage for plan implementation (MS).<br>Create an evaluation plan for implementation (CE).<br>Identify implementing organization for Plan strategies (AA). |
| **Stage III – Complete the CCC Plan** | |
| *Step 1* – Write the Plan. | |
| *Step 2* – Review the Plan. | |
| *Step 3* – Produce and disseminate the Plan. | |

**Appendix 2**

# Building Blocks of Comprehensive Cancer Control (CCC) Planning

| Objectives | Planning Activities | | | | | | | Outcomes | Planning Goal |
|---|---|---|---|---|---|---|---|---|---|
| **Enhance Infrastructure** | Assess infrastructure needs and capacity. | Gain buy -in from leadership of coordinating agency | Identify/ hire dedicated coordinator/ staff | Create core planning team | Involve other cancer -related staff of the coordinating agency/ ies | Develop work plan to guide the planning process | Coordinate and monitor the CCC process staff | •Management and administrative structures and procedures developed.<br>•Planning products produced, disseminated and archived | THE PLAN COMPLETED REVIEWED DISSEMINATED |
| **Mobilize Support (funding, resources, political will etc.)** | Assess current level of support | Secure funds and in -kind resources for planning | Build support among the public and private sectors | Publicize efforts of the partnership | Develop approaches for funding plan strategies | Reassess partnership representation and coverage for implementation | | •Partnership develops priorities for allocation of existing resources<br>•Gaps in resources and level of support identified | |
| **Utilize Data/Research** | Build linkages to registry and other data agencies and sources | Identify available data/ research | Review data and research as the basis for Plan objectives and strategies | Assess data gaps | Collect needed data if feasible &/or incorporate into Plan | Identify or collect baseline data against which to measure outcomes | | •Planning and research data reviewed for needs assessment and strategy development<br>•Data/research gaps identified | |
| **Build Partnerships** | Identify, contact, and invite potential partners | Assess partner interest and capacity | Prepare for first partnership meeting | Agree on goals, vision and decision -making process with partners | Establish partnership leadership | Create work groups | Assess partner satisfaction | Develop ways for new members to join & non -members to provide input | •Original members remain committed as new members join.<br>•Partnership/subcommittee meetings held and attended. |
| **Assess/ Address Cancer Burden** | Organize partnership around areas of interest | Determine critical areas of burden and high -risk populations | Assess gaps in strategies already in place | Create measurable goals and objectives for plan | Identify possible intervention strategies | Prioritize goals, objectives and strategies | Identify implementing organizations for plan strategies | •Target areas for cancer prevention and control selected and prioritized. | |
| **Conduct Evaluation** | Identify resources and staff for evaluation | Define planning evaluation questions | Document the planning process | Identify emerging challenges, solutions, and outcomes of the planning process | Provide TA/ training on evaluation to partners | Create evaluation plan for implementation | | •A strategy for assessing planning process, monitoring implementation, and measuring outcomes in place. | |

# Appendix 3. Findings for States Within Conceptual Areas of Comprehensive Cancer Control

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| ***Assess/Address Cancer Burden*** | | | | | | |
| **Target areas for cancer prevention and control are selected and prioritized. (PL)** | Work groups were established according to the anticipated structure of the plan. Had not yet begun to select and prioritize target areas as of the end of the study period. | Cross-cutting work groups were formed in the areas of Data and Surveillance, Legislation and Policy, Quality Assurance, and Awareness and Education. | Site-specific cancer work groups began developing priorities for breast, cervical, skin, colorectal, prostate, and lung cancer. Two cross-cutting work groups were also formed: Cross Cultural Competency, and Rehabilitation and Pain. | Draft plan was organized by cross-cutting issues: Prevention, Early Detection, and Cancer Care (including quality of life and end of life care). | Cross-cutting work groups were formed in the areas of Prevention, Early Detection, Treatment, Rehabilitation, and Palliation. Additional topics covered in the plan include Data and Cancer Surveillance, Implementation, and Evaluation. | Cross-cutting work groups in the areas of Prevention, Early Detection, Treatment, and Quality of Life have developed problem statements and begun selecting strategies. Groups plan to later reform into cross-cutting issue areas. |
| **Priority strategies are designed, implemented, and evaluated. (IM)** | No findings as of 1/2001. | Priority-setting work groups became action groups charged with implementing individual strategies under broad priorities as resources permit. Evaluation strategies are built into Action Reports developed for each strategy to be implemented. Partner organizations use the state's Action Plan to develop own strategies. | No findings as of 1/2001. | Exploring ways of implementing Plan strategies through existing means, such as Leadership Institute sponsored by American Cancer Society (ACS). | Some partners began working within their own organizations to pursue plan priorities as plan was being finalized. | No findings as of 1/2001. |
| ***Enhance Infrastructure*** | | | | | | |
| **Management and administrative structures and procedures are developed. (PL)** | A core team took responsibility for comprehensive cancer control during an extended period of organizational restructuring. An internal work group assisted by | The planning coordinator was supported by Prevention Block Grant funds. Both a core team (including the Chronic Disease Director) and an internal advisory group were formed. | A planning coordinator was funded at 1/4 time by the Prevention Block Grant. An intern, a core team, and an expanded team (including the Chronic Disease Director) supplemented the minimal staffing. | The health department (HD) contracted with the Kentucky Cancer Program (KCP) located at the University of Kentucky, University of Louisville Medical Centers, to write the state's comprehensive cancer plan. KCP | A CDC public health prevention specialist coordinated comprehensive cancer control activities. A 3-member core team received extensive support from the head of the Division of Community and Family Health and from health | A planning coordinator was hired through unobligated categorical funds. The coordinator was assisted by an *ad hoc* core team and championed by the Cancer Program Director. Support from the Division Director for chronic disease programming |

* PL = planning outcome; IM = implementation outcome; PR = program outcome; HD = Health Department.

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| | developing a preliminary vision statement, criteria for partners, and a proposed subcommittee structure. Categorical funds helped support a planning coordinator who worked closely with the Chronic Disease Director. Toward the end of the study period, a 40-member external task force was formed. | Illinois made extensive use of interns from local academic institutions, several of whom have continued to work at the Department of Public Health in various capacities after completing their degrees. Core team members facilitated work groups. External partners were active but not in formal leadership roles. | Other staff and partners served as: "backgrounders" (data experts both from within and outside the health department), work group facilitators (health department staff members), and work group spokespersons (non-health department staff members asked to represent their work group to the larger partnership). | developed a 3-member core team experienced in community outreach, research, and evaluation. A technical writer was later added. The Chronic Disease Director at the health department participated in team meetings and oversaw the contract. | department data staff. External partners assumed leadership roles throughout the process, both on work groups and for the cancer consortium as a whole. Some were affiliated with a pre-existing cancer advisory board to the Maine Bureau of Health (BOH). | has been strong. External partners have assumed leadership positions in work groups; partners facilitate meetings and disseminate minutes. |
| **Planning products are produced, disseminated, and archived. (PL)** | A draft vision and mission statement was distributed to the task force for review. Task force reviewed cancer plans from other states and an earlier state cancer control plan focused on breast cancer. | Illinois documented meetings and used the minutes as a forum for information exchange. A chronological log of planning events was maintained through regular communication and dissemination of materials to members by mail and e-mail. The statewide Action Plan was published in September 1999. | A file is maintained of planning documents, although it is not complete due to staff changes in the coordinator position. | KCP distributed the draft plan to a wide group of individuals and organizations involved in cancer control-related activities before and during the Kentucky CARE conference in September 2000. | Maine produced planning products steadily, including documentation of meetings. Planning materials were organized in a set of 3-ring binders. A chronological log of planning events was maintained, along with regular communications and dissemination of materials to members by telephone, mail, and e-mail. The statewide CCC plan was published in January 2001. | Utah maintained a file of planning documents, organized by meeting, with a separate binder for events leading to the first meeting. A chronological event calendar was maintained. Mailings were sent to partners with materials related to the meetings. E-mail was used to share the minutes of work group meetings with all partners. |
| **Sound yet flexible structures are in place, including structure for ongoing monitoring. (IM)** | No findings as of 1/01. | Illinois transformed work groups into action groups. A Resources Action Group was added to explore funding opportunities and the Quality Assurance Work Group was changed to Cancer Care Assessment Action Group to better reflect the group's activities. The core team was expanded to | No findings as of 1/2001. | No findings as of 1/2001. | Regular meetings of the work group chairs and the planning coordinator were added when it was observed that chairs experienced common issues and challenges. Coordinating committee was expanded to include additional external partners to prepare for implementation and transition to new body. Pre-existing cancer advisory group, a source of support and members for new consortium, | No findings as of 1/2001. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| | | include staff members from the cancer registry and interns. | | | was recast into an advisory role with the cancer registry. | |
| **Partnership members assume increasing responsibility. (IM)** | No findings as of 1/2001. | HD assumed responsibility for directing and facilitating the partnership. There were no formal external chairs for the partnership or its work/action groups; a few partners said they served as work group "chairs." Most partners expressed satisfaction with facilitation by HD staff and did not seem to seek greater responsibility. | No findings as of 1/2001. | No findings as of 1/2001. | Maine increasingly sought input from partners at key decision points. For example, Maine developed a volunteer *ad hoc* committee to join the Consortium Coordinating Committee in deliberations about program institutionalization. | No findings as of 1/2001. |
| **Partnership is a new entity - self-governing and greater than the sum of its parts. (PR)** | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. | A plan for institutionalization was developed for presentation to the Consortium in conjunction with publication of the CCC Plan in January 2001. | No findings as of 1/2001. |
| ***Mobilize Support*** | | | | | | |
| **Partnership develops priorities for allocation of existing resources. (PL)** | No findings as of 1/01. | Illinois is allocating existing resources on a strategy -by- strategy basis. When an action group elects to support a strategy, it is required to submit an action report that outlines existing resources available to support implementation or level of new resources required. | Objectives were prioritized within work groups (ongoing). | Recommendations are contained in draft Plan for future activities. | Maine developed a long list of cancer priorities supported by the Consortium. To implement, many will require coordination among existing resources rather than development of new resources. | No findings as of 1/2001. |
| **Gaps in resources and level of support are identified. (PL)** | Attendees at the initial task force meeting (8/16/00) were asked at the | Identification of resource gaps was linked to specific strategies in the action | HD recognized the need to enhance personnel resources to support CCC planning and | Kentucky CARE conference brought together individuals and organizations that are | Maine received a CDC field assignee. | Partners are considering ways to increase input from high-level representatives of organizations, providers, |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| | outset to signal organizational support and commitment to CCC planning and implementation.<br><br>Arkansas Cancer Summit (9/28/00) resulted in strong interest from potential and existing partners. This meeting also was a turning point in leveraging support from HD leadership. | reports. A Resource Action Group was established to identify funding opportunities and match them with specific strategies. Long-term staff support for CCC within the HD was being explored. | implementation, but did not receive its request for staff dedicated to CCC from the state or CDC. The state developed a budget and legislative issues paper and forwarded it to the director of the HD. | interested in supporting plan objectives and strategies. KDPH applied for a CDC field assignee (not received). | | insurers, minority groups, and pharmaceutical companies. An ongoing membership assessment process continually identifies potential new members who are then recruited. |
| **Existing resources are well utilized. (IM)** | No findings as of 1/2001. | Partners are supporting implementation of small-scale strategies within their own organizational purview. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. |
| **Resources for cancer control increase, as does coordination of the use of those resources. (IM)** | The cancer registry received additional funding and personnel after a presentation from the director of the cancer registry at a nearby model planning state. | A partner identified and obtained funds to support a specific strategy. Additional matching funds for this strategy were identified through the HD. Several other partners were pursuing relevant funding opportunities, sometimes working together in teams. Illinois attributed the receipt of additional personnel and funding for its cancer registry to CCC planning. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. |
| **Ongoing support for cancer control activities is secured (e.g., funding from general revenues). (PR)** | Arkansas received a CDC field assignee. Southeastern States American Cancer Society (ACS) /CDC Leadership Institute led to a commitment | A partner who is a legislator introduced a bill to support CCC with $500,000 in general revenue funds, although the bill did not make it out of | The American Cancer Society (ACS) made CCC a priority, approaching the HD about contributing support for a staff position. | No findings as of 1/2001. | A Prevention Specialist remained for implementation of the CCC plan as a CDC field assignee. Implementation includes strategy for institutionalization of CCC | No findings as of 1/2001. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| | from Arkansas-based ACS to be a co-partner to CCC in Arkansas. | committee. | | | initiative. | |
| | | | ***Utilize Data/Research/Evaluation*** | | | |
| **Planning data and research data are reviewed as a basis for needs assessment and strategy development. (PL)** | Identified sources include:<br><br>The Arkansas Breast and Cervical Cancer Program central database, behavioral surveys, county-level data.<br><br>As part of the Hometown Health Improvement project, each community conducting a needs assessment. | IL cancer registry staff lead or participate in action groups, are members of the core team and have made data presentations to the full partnership. The Data & Surveillance work group provided data to other work groups as requested. | Designated "backgrounders" (data experts) compiled and presented available data on incidence, prevalence, and mortality to each work group. Backgrounders assisted with the baseline data needed for specific objectives developed by each work group. | Core team members reviewed data on cancer incidence and mortality in Kentucky to focus on priority areas. | The medical director of the cancer registry is an active member of the CCC core team. BOH staff provided cancer registry and other HD data to work groups for review in priority-setting activities. Some partners (e.g., the Hospice Association) shared data with relevant work groups. Work group requests for scientific literature were fulfilled by the planning coordinator (a CDC employee) who had access to CDC library services. | Some background data were provided to partners at the first meeting (e.g., BRFSS, other sources). The Utah Cancer Registry is an active partner in the treatment work group. The Registrar gave a presentation to the Partnership at the second meeting about data available from that source. Work groups are collecting and reviewing data as they work to develop their problem statements. |
| **Data/research gaps are identified. (PL)** | Concurrent with CCC planning, the cancer registry has undergone its own complementary improvement process (see implementation below). | Strategies in the state cancer prevention and control plan include techniques to improve melanoma reporting (working closely with the dermatological professional association), several strategies that involve new data collections, and a strategic plan to enhance the cancer registry over time. | Work group members proposed data elements to be added to existing data sources. The skin cancer work group proposed (1) adding to the BRFSS a question to collect baseline data on skin cancer and (2) adding to the cancer registry incidence data on basal cell and squamous cell carcinomas. | Several priority areas in the state cancer prevention and control plan call for further research (e.g., research on environmental carcinogens). | One section of the Maine cancer plan is devoted to addressing data gaps and strengthening data resources. The Prevention Work Group in Maine was concerned about lack of evidence on the effectiveness of prevention. Data were particularly sparse for areas farthest along the continuum of care (such as rehabilitation) where little surveillance has been done. | Work groups determined what baseline data were needed to support the development of problem statements. |
| **Data and research are used to support priority setting. (IM)** | No findings as of 1/2001. | Data were used to select target cancers and to prepare Cancer-at-a-Glance and county cancer profiles. A cancer data book was prepared in cooperation | No findings as of 1/2001. | No findings as of 1/2001. | Work groups reviewed available data to identify areas to target for action and to develop issue statements, goals/ objectives, and strategies in these target areas. Where work group members | No findings as of 1/2001. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | |
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| | | with ACS. Data development, enhancement, and use are a focal point of the Data and Surveillance action group. | | | could not identify sufficient data to inform their decisions, they included new research and new data collection among their proposed objectives and strategies. | |
| **Gaps in data and research begin to be addressed. (IM)** | An invited presentation by Tom Tucker of the Kentucky cancer registry generated support for adding funds to the budget of the Arkansas registry for developing community-level data and for using data for planning. | New data collections have been initiated on the needs of local health departments and on the location of mammography screening sites in Illinois. A new melanoma reporting strategy is in place. | Identification of a lack of adequate behavioral baseline data for some cancers led to the addition of questions to BRFSS. | No findings as of 1/2001. | No findings as of 1/2001. | No findings as of 1/2001. |
| **Cyclical process in place to assess, strategize, prioritize, implement, evaluate. (PR)** | No findings as of 1/2001. | A decentralized process for management, monitoring, and evaluation of implementation is established with responsibility resting in action groups. | No findings as of 1/2001. | No findings as of 1/2001. | Maine has identified staff members to support centralized procedures for the management, monitoring, and evaluation of implementation. | No findings as of 1/2001. |
| ***Build Partnerships*** | | | | | | |
| **Original members remain committed as new members join. (PL)** | About 40 partners attended first task force meeting on 8/16/00, followed by Cancer Summit on 9/28/00 where 90 additional individuals expressed interest in participating in the summit as external partners. Arkansas currently is deciding how to include different levels of participation in the summit to receive maximum input without becoming | The Illinois partnership consists of 60 external members (including several legislators). New members continued to join often after hearing about the partnerships at conferences or speaking events. | The Kansas partnership consists of 30 -- 40 members. New members continued to join - at the June 2000 meeting there were five individuals attending for the first time. | Kentucky did not elect to develop a partnership for CCC planning. The core group obtained input from stakeholders as it developed the draft plan. | The planning consortium consisted of about 50 member organizations with room for additional growth.<br><br>As the CCC plan is implemented the transitional body will retain original consortium members while new members will join. | The Utah partnership consists of approximately 60 members. New members continue to join. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| | unwieldy. | | | | | |
| **Coalition and subcommittee meetings are held and attended regularly. (PL)** | The work group/ subcommittee structure was established at the second task force meeting held in October 2000. | Partnership and work group meetings were held regularly throughout the priority-setting process. Since publication of the plan, full partnership and some action group meetings are held less frequently. (Some HD staff members serving as work group facilitators were assigned to new duties and had to be replaced.) | Partnership and work group meetings have had good attendance, with work groups meeting on an as-needed basis between the partnership meetings held every 3 to 6 months. | No findings as of 1/2001. | Consortium meetings were held quarterly and work group meetings more frequently throughout planning process. The coordinating committee met almost monthly between consortium meetings to discuss emerging issues and strategize. Work group chairs met regularly as a group with the planning coordinator when setting priorities for the plan. | The partnership meets approximately quarterly and the work groups more frequently between partnership meetings. |
| **Members commit to and are accountable for implementation of the plan. (IM)** | No findings as of 1/2001. | Accountability for plan implementation rests with the action groups rather than with individual members. Action groups are currently implementing strategies for which funding and other support has been identified. | No findings as of 1/2001. | No findings as of 1/2001. | At the consortium meeting in February 2000, members signed up to indicate their willingness to support implementation for specific goals and their objectives. | No findings as of 1/2001. |
| **Coordination betweenprograms and services improves and the atmosphere grows more collaborative. (IM)** | A small group associated with an earlier planning process questioned the need for a new CCC plan. A review of the old plan by the task force led to a consensus that it was not comprehensive in scope and to the decision to move forward with CCC. | Advocacy groups that had been in disagreement in the recent past had became active members of the partnership. Hospitals that in the past refused to work with one another have now agreed to work and together with a newly formed cancer center that is an active partner. | Partners brainstormed on ways of bringing in representatives from organizations not at the table. | Kentucky was completing a statewide breast cancer planning effort at the same time that it began CCC planning. Several participants in the Governor's Task Force on Breast Cancer stated that they saw their issues overlapping with those of cancer control in general. | Work group chairs worked together to make decisions for the plan as a whole, rather than focusing solely on the objectives for a specific work group's issues. | The partnership includes a broad base of partners, including some in public and private sector leadership roles. |
| **Partners advocate and act in a concerted manner and themselves adopt a** | No findings as of 1/2001. | Partners advocated for support for CCC in the state legislature, with their federal legislative representatives, and | No findings as of 1/2001. | No findings as of 1/2001. | Consortium leadership is committed to implementation of the state plan and to institutionalization of the initiative. One partner has | No findings as of 1/2001. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| **comprehensive approach. (PR)** | | elsewhere. Partners also assisted in identifying funding for specific projects. Individual partner organizations reported using the Illinois state plan as a framework for focusing their own work in cancer prevention and control. | | | agreed to in-kind contributions to support program institutionalization. Partners made presentations at the consortium about using the state cancer prevention/control plan as a model for developing internal plans for achieving joint priorities. | |
| ***Institutionalize Initiative*** | | | | | | |
| **Members represent broad base and all believe they are being heard and benefiting. (PL)** | The Cancer Summit resulted in a broad base of support for planning as evidenced by the number of people who responded to a request to drop off cards stating interest.<br><br>Task force members disagreeing with comprehensive approach were invited to air their concerns. Leadership used a consensus-building process that resulted in commitment to a CCC Plan. | The Partnership is considered to be broad and representative. Greater input may be desirable from representatives of minority and grass-roots organizations, and from cancer center directors and academics. | The Partnership has broad representation from a variety of organizations from all of the urban areas, but involvement of rural area representative remains a challenge. Members state that they feel comfortable bringing their issues and agendas to the table. | During Kentucky CARE conference, participants decided that the plan would be implemented through the coordinated actions of individual organizations and their ongoing relationships rather than through a new Partnership structure. | The Consortium is broad and representative. Strong clinical representation was achieved due to active recruitment by the cancer registry medical director and consortium co-chair, themselves physicians. One partner expresses concern that geographic representation was not broad enough, and involving cancer survivors has been a challenge. Partners have input into all major decision- making. | The Partnership has broad representation of the key organizations in the state. However, some participants expressed concern that some representatives are difficult to include as active members. This includes those in high-level positions (e.g., in medical centers). Recruitment is ongoing, and new organizations and members continue to join who can fulfill active roles. |
| **Members and facilitators express satisfaction with the process. (PL)** | Support increased support at the health director level after the September Cancer Summit. | A recently administered survey of partners revealed satisfaction with the CCC process. Partners and core team members voiced enthusiasm for the process and their respective roles in it. | Partners and core team members thought the large group meetings were organized and productive. A training for facilitators helped to focus and clarify the roles of the work groups and contributed to improved satisfaction. | Kentucky CARE conference garnered an enthusiastic response from participants. | Partners and core team members thought the large group meetings were well organized and productive. Those interviewed also voiced enthusiasm for and satisfaction with the process as a whole and with their respective roles in it. | Partners and core team members thought the large group meetings were well organized and productive, particularly through the use of a trained facilitator for the first few meetings. Work group members were pleased with their progress, but some groups thought that more direction would be helpful. |
| **Partnership is** | No findings as of | Core team members are | No findings as of | District Cancer Councils | CCC initiative has support | No findings as of 1/2001. |

| Outcomes* | Arkansas | Illinois | Kansas | Kentucky | Maine | Utah |
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| **visible and a focal point for cancer-related policy and activities. (IM)** | 1/2001. | frequently invited to present at meetings and conferences. A CCC exhibit draws attention at events. The CCC planning coordinator fields inquiries to the HD on cancer-related matters. A CCC web page at the HD site links to other relevant HD sites. Several partners were invited to the President's cancer panel regional meeting. | 1/2001. | exist throughout state, but their role in implementation of the CCC plan is unclear. | among HD management, the ACS region, and consortium members. A core team member was invited to the President's cancer panel regional meeting. | |
| **Mechanisms are developed to ensure the collaborative process is sustainable. (IM)** | No findings as of 1/2001. | The Chronic Disease Division is seeking funding from health department management for one or two permanent staff positions for CCC. | No findings as of 1/2001. | No findings as of 1/2001. | From early in the CCC process, partner input was sought at key intervals; the coordinating committee developed matrices for decision-making and invited partners to discuss options. Partners and core team members are developing an approach to implementation and institutionalization, as outlined in the state cancer plan. | No findings as of 1/2001. |